Arthritis and disability

Prepared for:

Arthritis Australia

October 2014

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Abbreviations

AA	Arthritis Australia
AS	Ankylosing spondylitis
CRPD	UN Convention on the Rights of Persons with Disabilities
CRS	Commonwealth Rehabilitation Services
DVA	Department of Veterans Affairs
GP	General Practitioner
HACC	Home and Community Care
ICF	The International Classification of Functioning, Disability and Health
JIA	Juvenile idiopathic arthritis
OA	Osteoarthritis
PBS	Pharmaceutical Benefits Scheme
PA	Psoriatic arthritis
RA	Rheumatoid arthritis
SPRC	Social Policy Research Centre
SP	Spondyloarthropathy
SLE	Systemic lupus erythematosus
SS	Sjögren's syndrome
VI	Vision impairment
WHO	World Health Organisation

Acknowledgements

The research team would like to thank the people who generously shared their personal experiences with us, both through interviews and by completing the online survey. We would also like to thank Arthritis Australia, the Project Advisory Group and the Consumer Roundtable for their direction and contribution to this research.

In addition we would like to thank the arthritis organisations in each state and territory for their assistance in recruiting participants for interview and promoting the online survey.

This report was prepared for Arthritis Australia by the Social Policy Research Centre, UNSW Australia. The research was funded by an unrestricted grant from The Medicines Australia Community Chest to Arthritis Australia. The Community Chest supporters are AbbVie Pty Ltd, AstraZeneca Pty Ltd, Janssen-Cilag Pty Limited, Medicines Australia, Pfizer Australia Pty Ltd and Roche Products Pty Ltd.

Executive Summary

linguistically diverse community[1] were under represented. This is likely to reflect the membership base of the organisations through which participants were recruited.

The information provided by participants was analysed thematically against the rights in the UN Convention on the Rights of Persons with Disabilities in the areas of health, habilitation and rehabilitation, work and employment, standard of living and social protection, and family and social participation. In addition the Personal Wellbeing Index was used to measure participants' quality of life and compare it with that of the Australian population as a whole.

The breadth of the analysis was based on the information provided by the participants and therefore may not be comprehensive across all themes. The findings of the research have not been prioritised as

- Almost half of participants had another health condition or disability which complicated the management of their arthritis and vice versa, particularly in relation to medication.

- Participants reported that pain and fatigue were overlooked in the treatment of their arthritis and few participants were offered options or advice on managing these symptoms.

- Effective arthritis management usually requires a team of health care professionals but accessing them is often difficult and expensive. Participants also reported that health services were complex and fragmented, and that they experienced difficulties navigating services and finding an appropriately skilled provider that met their needs.

- Living with arthritis adversely affected emotional wellbeing both for the person with arthritis and their carer, and this was often ignored in their treatment plan.

Habilitation

The research investigated people's access to habilitation and rehabilitation.[2] The research found:

- Nearly all participants (95 per cent) reported that their arthritis limited their ability to engage in daily activities, with 37 per cent reporting that they were always limited and 54 per cent reporting that they were sometimes limited in their ability to engage in daily activities due to their condition.

- Participants who identified as either always or sometimes having limited ability to engage in daily activities as a result of their arthritis then identified which activities were most affected: 34 per cent said their arthritis had a severe or profound impact on being able to manage their home or garden, 22 per cent on being able to undertake domestic activities, and 5 per cent on undertaking basic personal care.

- Participants reported making a range of changes to their living circumstances to accommodate their arthritis, from buying aids and equipment, modifying their homes, to relocating to more accessible homes.

[2] Habilitation is services that help a person learn, keep, or improve skills and functional abilities that they may not be developing, for example using a cane, guide dog or sign language. Rehabilitation is services that help a person improve skills that have been lost, for example regaining lost skills or functioning after a stroke or head injury.

Work and study

The research investigated people’s experience and the barriers and facilitators to accessing and maintaining employment and study. The research found:

- Participants reported that the ability to participate in the workforce was important for social participation as well as to meet medical costs and maintain an adequate standard of living.

- Of the participants who were of working age (aged less than 65 years, 63 per cent), 74 per cent were employed full or part-time (57 per cent full-time and 43 per cent part time), 37 per cent were not in the labour force, and 15 per cent were studying full or part-time.

- The labour force participation rate for survey participants was 44 per cent, compared to the national participation rate of around 65 per cent. People who were younger when the condition started were more likely to be out of the workforce than those with onset at a later age.

- 67 per cent of all participants reported that arthritis had affected their work or study, now or in the past; 23 per cent reported that they were permanently unable to work or study because of their condition; 68 per cent were restricted in the type of work or study they could do; and 65 per cent were restricted in their hours of work or study. In addition, 35 per cent reported that they required workplace modifications and 14 per cent reported that they needed ongoing assistance to participate in work or study.

- Nearly all participants of ns and h;ly alldr per,2a1(n the d [(of)5e0.7(s)-1.7(tudy)]TJ -0.0e 7(e)-

have experienced symptoms at a much younger age than those who were employed.

- The extent to which people were able to work or study depended on whether they needed to and were able to work flexibly, work reduced hours, or have access to a modified workplace.

Standard of living and social protection

The research investigated the implications of people's lived experience of arthritis in terms of being able to attain and maintain an adequate standard of living for themselves and their family. The research found:

- Participants reported that the financial consequences of arthritis were detrimental due both to the high

Family and social participation

The research investigated people's experience, barriers and facilitators of being included and participating in their family and community. The research found:

- The extent to which people's family and social participation was affected by their arthritis depended on the level of impairment caused by their condition, personal circumstances, and the availability of informal and formal support at home and in their place of work or study.

- Nearly all participants (84 per cent) identified informal support from immediate family members as their main source of support for personal care, domestic activities and managing their arthritis. This was due to the proximity of family, the lack of access to flexible services, or because they could not afford formal services due to reduced income.

- For people whose arthritis caused significant disability, greater formal support at home, work or study would improve their social participation.

- Arthritis affected children – they may have arthritis themselves or they may have a sibling or parent with arthritis, affecting family dynamics or requiring them to take on caring responsibilities.

- Some women chose not to start a family because of their arthritis, as the prolonged period off their medication could have long-term effects on the severity and prognosis of their condition.

- The impact of arthritis was not limited to the people with arthritis but also affected their carers, family, neighbours and friends:

    - physically, especially older carers who are also likely to have arthritis or other health conditions

    - emotionally – in terms of isolation, changed relationships, financial hardship, and the impact on their own social participation

    - financially – in reducing or limiting their capacity to work.

Services and support needs

Participants identified a number of service and support needs concerning information requirements, informal support (family and friends, community and arthritis support groups), formal support (health care, medication, social protection and home care), and other areas (employment, home modifications, equipment, and public awareness).

- People with arthritis, their families and carers, need access to better information about their condition, including: medication and side effects; managing pain and fatigue; support groups and emotional support available; aids and equipment and how to source them; and the availability of social and disability services and how they can be accessed.

- Some participants with arthritis rely heavily on informal support, in particular from family and friends. Family and friends need to be supported to be able to sustain this role.

- Increased community awareness and understanding of arthritis – including amongst health practitioners, policy makers and employers – could also improve support for people with the condition.

- Local or online support groups help meet the needs of people with arthritis and could be expanded to target specific age groups and conditions.

- There is a clear need to identify and improve formal support, from providing better ongoing health care beyond diagnosis, increasing the coverage of necessary medications under the PBS, to improving awareness of the disabling impact of arthritis in the provision of social protection and social services.

Increasing recognition in the broader community of the nature and impact of arthritis, and the fact that it affects people of all ages – and not just older people – would help address many of the service and support needs identified.

Implications of this research

This report reflects the voices of people with arthritis who are trying to hold down a job, raise a family, and participate in the life of the community, while managing the disabling effects of their condition. They face significant challenges due to the complexity and fragmentation of health services, inflexibility in the social support sector, and limited awareness in the community of the impact of living with arthritis.

Many people with arthritis experience disability and require support – both short-term and long-term – depending on the nature of the condition, the impact it has on them, and their personal circumstances.

It is not clear to what extent the National Disability Insurance Scheme (NDIS) will support people with arthritis or whether any existing support services provided will be affected. A risk is that where services (from State and other providers) are transitioning to the NDIS, access to support currently available might be reduced.

This research suggests that:

- The disabling impacts of arthritis need to be recognised in the community as well as by government, service providers, employers and educators.

- The NDIS should recognise the severely disabling and fluctuating effects of arthritis. Some people with arthritis will need NDIS individual packages.

- Other formal support services need to be identified for people with arthritis,

1 Introduction

Arthritis Australia commissioned the Social Policy Research Centre (SPRC) at UNSW Australia to undertake research on the lived experience of people with arthritis and other musculoskeletal conditions. The aim of this research was to increase understanding of

arthritis (including lost productivity and wellbeing) was estimated at $24 billion (Access Economics 2007).

1.2 Arthritis and disability

Arthritis is the second leading cause of disability and the leading cause of chronic pain in Australia. Nearly 600,000 people, or 15 per cent of all those with disability, report arthritis as their main disabling condition (ABS 2012). Of these, one in four experience severe or profound core activity restrictions (ABS 2010).

Arthritis-related problems include pain, fatigue, stiffness, inflammation and damage to joint cartilage – the tissue that covers the ends of bones enabling them to move against each other – and surrounding structures. As a result, people with arthritis can experience significant loss of function, notably manual dexterity, strength and mobility; deformity; and pain and fatigue. Arthritis can interfere with a person's ability to undertake basic daily living tasks and can have a significant impact on their quality of life. Different types of arthritis can cause varying degrees of functional impairment. Impairment is usually chronic and progressive and is often overlaid with 'flares' of disease activity which cause unpredictable, episodic bouts of severe pain, immobility and functional decline, interspersed with periods of reduced disability or disease remission.

The impact of arthritis on a person can vary significantly, depending on a number of factors including: type of arthritis; age at onset; any delay in diagnosis; treatment received; general health; the extent of joint damage and deformity caused; the side effects of long-term medication; an-1.7J 0 Tw 8.18

- how people are affected (people with arthritis and their carers) physically, emotionally, socially and financially
- what helps people affected to manage the impact of their condition, and
- how support for people with arthritis-related disability can be improved.

This study explored the experiences of people living with a variety of arthritis types including osteoarthritis and inflammatory forms of arthritis such as rheumatoid arthritis, ankylo

person with impairments which are chronic and / or episodic in nature may be considered to have a permanent disability[3], it is not yet clear how people with arthritis will fare in the scheme's assessment processes. In the past for example, some people with arthritis have been denied access to disability services because their condition has been considered a medical condition and not a disability, despite the associated activity limitations.

While most people with arthritis will not require an individualised package of support, a substantial number will have significant disability warranting long-term support (Tier 3). Others will be assessed as Tier 2 participants. Current indications are that Tier 2 participants will need to rely on existing systems of referral and support.

2 Research design

The research used a multi-method approach to provide a comprehensive account of the disabling impacts of arthritis on the lives of people with different forms of arthritis, their families and carers. The focus is on what support people need to maximise their quality of life and participation.

Ethics approval was obtained from the UNSW Human Research Ethics Committee (Reference HC13115). All research participants

- People’s experience of being included and participating in family and society and the identification of any barriers and facilitators.

Two gaps that were identified in the literature review were the impact of arthritis in life areas aside from work (the impact on workforce participation is well documented – see Appendix A: Literature review, section 3.3) and the impact of juvenile idiopathic arthritis (beyond treatment, for example in terms of education, family life, and participation). Both warrant more detailed investigation in the future.

The full literature review is attached at Appendix A: Literature review. Both the gaps and the key findings of the literature review are explored in this research through the roundtable and in-depth interviews.

2.2 Consumer roundtable

The consumer roundtable was held in June 2013 and involved 13 participants, including one carer and one arthritis educator. Participants were predominantly women (2 men attended), came from different States, and had different types of arthritis. The group discussed the lived experience of arthritis in the context of the core objectives of the CRPD, particularly health, habilitation and rehabilitation, work and employment, standard of living and social protection[4], and participation (social and family). A summary of the issues raised is attached at Appendix B: Summary of roundtable.

2.3 In-depth interviews

The interviews aimed to understand the experience of the person with arthritis and the impact it had on their everyday life. The interviews used a ‘discovery interview’ format (Ali and Gray 2006), which encouraged individuals to tell the story of their experience, rather than answer prescribed questions. The standardised structure adapted from Ali and Gray 2006 was used to offer prompts to participants to assist them to tell their story. It describes the chronological stages of a person’s journey through an illness or disability and aims to trigger significant memories. The prompts used were:

- Type of arthritis
- Initial symptoms, how soon it was diagnosed and how it is treated

[4] Social protection, as defined by the United Nations Research Institute for Social Development, is concerned with preventing, managing, and overcoming situations that adversely affect people’s wellbeing. Social protection consists of policies and programs designed to reduce poverty and vulnerability by promoting efficient labour markets, reducing people's exposure to risks, and enhancing their capacity to manage economic and social risks, such as unemployment, exclusion, sickness, disability and old age.

- How arthritis has impacted on everyday life in terms of home, being part of the community, and work life, and what changes have been made
- What support is offered now
- What support was not provided but could have helped

3 Frameworks for analysis

3.1 UN Convention on the Rights of Persons with Disabilities

Australia ratified the UN Convention on the Rights of Persons with Disabilities (UNCPRD) in 2008. The UNCRPD is a significant legal and policy advance establishing legally binding obligations for those states that become a party to the Convention. The Convention establishes international standards in a human rights framework that affirms people with disabilities as rights bearers rather than objects of welfare.

The UNCRPD recognises disability as a part of human diversity and embraces a whole of government approach. The Convention recognises the dynamic relationship between impairment and disability where a person's impairment can limit their ability to engage in daily life activities. Central to its implementation is recognition of the importance of specific impairment related supports in parallel with broader infrastructure and non-discrimination measures.

Implementation of the UNCRPD has been the basis for and guiding framework of much recent policy development in Australia. The National Disability Strategy and the National Disability Insurance Scheme are central pillars of Australia's implementation of the Convention. These policies recognise the right of people with disability to be participating members of their community. The UNCRPD rights recognise the need for people to receive appropriate supports and reasonable adjustments to be able to participate meaningfully. Rights such as health, habilitation and rehabilitation, education and employment, standard of living, and family and social participation, provide a framework for an inclusive and accessible society that respects the rights of persons with disability.

The rights established under the UNCRPD were used for the thematic analysis of the data gathered from the literature review, consumer roundtable, in-depth interviews and survey.

3.2 Appreciative inquiry

Appreciative inquiry is a form of analysis that seeks to identify what is working, rather than merely identifying problems (Rogers & Fraser 2003). Appreciative inquiry begins by using stories of positive experiences to identify themes and what has helped people to achieve their goals. Participants are not led or directed in any way.

The age distribution of participants in this research was similar to that of the Australian population with arthritis although the research captured less of the 75+ age group compared to other age groups. This may have been due to the online format of the survey (although paper copies were provided on request), the length of the survey, and the way in which the survey was distributed (mainly via Arthritis organisations, possibly reflecting their membership).

The survey results confirmed that arthritis is not only an older person's disease, with 16 per cent of survey participants being less than 45 years old and 64 per cent under 65 years old and therefore of working age.

Women were over-represented in this research, comprising 84 per cent of research participants compared to 60 per cent of all people with arthritis.[6] Again, this

Table 4: Age when first experiencing symptoms of arthritis, by type of arthritis (% of survey participants)

Years	Rheumatoid arthritis %	Juvenile idiopathic arthritis %	Osteoarthritis %	Psoriatic arthritis %	Ankylosing spondylitis %	Other forms %
Under 25	20	89	13	33	55	26
25-34	20		14	28	21	22
35-44	23	11	21	17	14	21
45-54	20		29	13	10	20
55-64	13.5		16	9		8
65-74	3		6			2
75+	0.5		1			1

Source: Survey, Section C – Your arthritis

Notes:
Includes people with more than one type of arthritis – age at first symptoms of arthritis
Results for JIA are not statistically comparable due to the small number of people identifying as having JIA (n=9).